Health Care of Children with Autism

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AAIDD June 2012
Overview

- Context of health care services for children with autism
  - Importance of Medicaid and states’ financial prospects
- Costs of health care for children with autism are expensive
  - To the public health system
  - To families, which have limited capacity
- Marked inadequacies in health care access for children with autism
  - Particularly troubling racial and ethnic disparities in quality of care
- “New” autism insurance mandates in the states: are they working?
Insurance coverage of children with autism

Private only 47%
Public only 32%
Public & private 15%
Other 3%
Uninsured 3%

Source: Chiri & Warfield (2011)
How are the states doing?

- 43 states are projected to have FY2012 spending above FY2011
  - But half the states have not recovered to pre-recession levels
  - The recovery is well underway, but not as robust as previous recoveries
- Expiration of the 2009 American Recovery & Reinvestment Act funds challenges states, particularly in Medicaid ($87 billion)
- States must solve budget gaps of $146.3 billion in fiscal 2011 and 2012
  - Increasing demand for state services has not been fully offset by increasing revenue projections
- Medicaid (still) represents the single largest expenditure for state budgets (24% of total spending in FY11)

Source: NASBO & NGA, 2012
Average annual Medicaid growth

Source: National Governors Association & National Association of State Budget Officers
Number of states proposing Medicaid cost containment strategies, FY 2012

Source: National Governors Association & National Association of State Budget Officers, 2012
Total annual Medicaid expenditures per 10,000 covered lives

Source: Wang & Leslie, 2010
Note: 2003 dollars
Maternal employment & family income

- Mothers of children with autism earn 35% less than mothers of children with other health limitations

- Mothers of children with autism work fewer hours if they work at all

- Earnings of families raising children with autism are 21% below families of children with other health limitations and 28% below families of nondisabled children

Source: Cidav et al. (2012)
Family financial burden

- Reduced/stopped employment to pay for child's care
- Paid >$1000 for medical care last year
- Needed add'l income for child's care last year
- Child's HC caused financial problems for family

**Note:** p<.05 for all; SHCN=special health care needs

**Source:** Kogan et al., 2008
Families lack adequate financial resources

- On average, families of children with autism and other developmental disabilities have liquid savings (cash available) of <$500
- This level of savings is consistent across age of parents
- Particularly worrisome: how will these families weather a health or unemployment crisis?

Source: Parish et al., 2010
Median income and assets among parents of children with DD by parental age cohort

Source: Parish et al., 2010
Families struggle securing autism care

- > ¼ of families report not knowing if they live in a state with an autism mandate
- > ½ of families report not knowing how their own health insurance policy is regulated by the autism mandates
- > ¾ of families are frustrated by the red tape involved in processing medical bills and reimbursements
- 86% of families would use more needed care if reimbursement challenges were addressed

Source: MedClaims Liaison & Autism Speaks
State Medicaid spending & families’ financial burden

- State Medicaid spending for children with disabilities is critically important
- Families of children with autism in states with higher per capita Medicaid spending are less likely:
  - To have ANY out-of-pocket expenses for their child’s health care
  - To have out-of-pocket > $500 for the year
  - To have spending that > 3% of their total annual income
  - To need additional income to care for their child

Source: Parish et al., forthcoming
Health care access of children with autism and other special health care needs

Note: p<.05 for all; SHCN=special health care needs
Source: Kogan et al., 2008
Racial disparities in quality of care for children with autism

Source: Magaña et al, forthcoming; all comparisons with White children p<.05
States with private autism insurance reform laws

Source: Autism Votes, 2012
New autism mandates reduce families’ financial burdens

Families living in states with autism health insurance mandates:

- Are less likely to spend >$500 annually for out-of-pocket health care costs of their child with autism
- Are less likely to have any out-of-pocket costs

Source: Parish et al., 2012
Conclusion

The time for advocacy has never been more pressing

- State budgets will continue to be strained
- Families continue to struggle to
  - Secure services for their children with autism
  - Stay afloat financially
- Interventions to improve health care access for racial and ethnic minority children with autism are urgently needed
  - Policies must promote high-quality care
- The Supreme Court’s decision and the DSM-5 diagnostic changes may or may not reduce access to services
Acknowledgements

- Co-authors: Sandy Magaña (University of Wisconsin), Jamie Swaine, Kathleen Thomas, Rod Rose (University of North Carolina at Chapel Hill), Maria Timberlake (Brandeis)
- Maternal & Child Health Bureau, HRSA grants R40MC19927 & R40MC22647

Thank you!